Disordered eating patterns in coeliac disease:

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Disordered Eating Patterns in Coeliac Disease: A Framework Analysis

OBJECTIVE: The need for dietary-management in coeliac disease may lead to the development of disordered eating patterns. A theoretical model of disordered eating has been proposed to explain disordered eating in coeliac disease. The aim of this study was to explore the experiences of typical and disordered eating in coeliac disease to gain a greater understanding of these processes and explore specific pathways within this model.

METHODS: We interviewed 21 individuals with coeliac disease, recruited from a previous database, about their experiences with food and food environments. Information about disordered eating status was assessed via questionnaire. The interviews were analysed qualitatively using Framework analysis, which was underpinned by the theoretical model of disordered eating in coeliac disease.

RESULTS: Experiences differed between participants scoring high on measures of disordered eating and those who scored low (typical eaters). Participants scoring high on measures of disordered eating were concerned about the consequences of their gluten-free diet on body image and they described eating patterns similar to binge/restrict cycles. Typical eaters reported being able to integrate their dietary self-management into their daily lives; however, general concerns around food and cross-contamination were associated with a restriction in food intake.

CONCLUSIONS: Coeliac disease has a varied impact on eating patterns. The need to follow a gluten-free diet and to be vigilant around food has to be balanced with concerns around food availability and cross-contamination which have the potential to contribute towards disordered eating attitudes and behaviours. The findings suggest that the theoretical model of disordered eating provides an adequate explanation of disordered eating patterns in coeliac disease.

Coeliac disease (CD) is a life-long condition characterised by flattened villi (villous atrophy) and inflammation of the small intestine ([1]). These intestinal changes occur in response to the ingestion of gluten, which is formed from two proteins: gliadin and glutenin ([2]). Gliadjn is the toxic protein for individuals with CD, as are structurally similar proteins hordein and secalin that are found in barley and rye. The symptoms of CD can be both gastrointestinal and non-gastrointestinal and include nausea, bloating, cognitive impairments and weight changes ([1]). There is no cure for CD but the condition is managed by following a life-long gluten-free diet (GFD), which requires the exclusion of wheat, rye, barley and sometimes oats from the diet. Management of the GFD also requires vigilance around cross-contamination of food products, as small amounts of gluten can cause symptoms in some individuals ([3]).

In the majority of people with CD, successful management of the GFD reverses damage to the gut and reduces symptoms. However, the GFD can be challenging to follow and can create concerns around eating outside the home and cross-contamination of food products ([3]). Although the GFD is physically beneficial for the individual, its restrictive nature may impact quality of life and result in maladaptive behaviours, including disordered eating patterns ([4-6]).

The majority of individuals with CD score in the healthy range on self-report measures of disordered eating ([7,8]). However, for some, CD may act as a risk factor for the development of disordered eating via a number of mechanisms. Factors essential in managing the GFD, including food preoccupation and awareness, may harm relationships with food ([9]). Additionally, factors relating to the diagnostic experience, including gastrointestinal symptoms and changes in weight, may affect body image and eating patterns ([10]). Alternatively, the non-specific burden of chronic illness may account for the presence of disordered eating in this population. Satherley, Howard and Higgs ([8]) suggest that factors both unique to the CD diagnosis (gastrointestinal symptoms, dietary management) and nonspecific factors (psychological distress) are important factors in disordered eating and CD.

This study was theoretically informed by Satherley, Howard and Higgs' ([6]) model of disordered eating in gastrointestinal disease (see Figure One). Central to this model are two pathways; the first pathway describes individuals who experience anxiety around food and

cope with this by consuming a limited variety of gluten-free foods. The second pathway describes those who struggle with weight changes experienced after diagnosis (usually weight gain) and engage in poor dietary self-management to promote gastrointestinal symptoms and associated weight loss. In an evaluation of this model, dietary-management and gastrointestinal symptoms were associated with disordered eating scores, lending some support to pathway two ([8]). However, the relationships between gastrointestinal symptoms, dietary-management and disordered eating were not clear. Furthermore, no evidence was found to support pathway one, the role of anxiety in disordered eating. This was attributed to a lack of appropriate tools to measure concerns around food in individuals with CD. Understanding these factors and their role in the development of disordered eating is essential if appropriate supportive strategies are to be adopted by healthcare professionals.

The present study aimed to gain a holistic view of the experiences of typical and disordered eating in CD. This was done by exploring the pathways of the Satherley, Howard and Higgs ([6]) model by using a structured framework. According to the model, the type of disordered eating pattern that develops will depend on beliefs about CD and the GFD, as well as the psychological response to weight changes after CD diagnosis. By using this model to create the framework for the interviews, we were able to assess how well this model was supported by qualitative data.

Method

Participants (18-69 years) with a self-reported biopsy-confirmed diagnosis of CD, for at least 2 years, without additional food allergies or health conditions, were eligible to participate. Purposive sampling was used to recruit both typical and disordered eaters from a previous database. Participants who scored above 20 on the EAT-26 or above 17 on the BES were categorised as disordered eaters (DE), participants scoring below were classified as typical eaters (non-DE; [11,12]). The EAT-26 is a screening tool that measures symptoms and concerns characteristic of eating disorders and the BES screens for the presence of binge eating behaviour, high scores are associated with more disordered eating symptoms and behaviours. These are not diagnostic tools but screen for the presence of disordered eating behaviours. The measures of disordered eating were taken between 18-63 days (mean = 41 days) prior to the interviews.

Sample size was based on data saturation, by repeatedly comparing data across participants, which occurred when no new information was obtained from the interviews ([13]). Twenty-five participants were invited to take part in the interviews but three withdrew their data and one was removed from analysis, as the inclusion criteria were not met. Individuals who withdrew their data were all classified as disordered eaters, no other demographic differences were found in this group. Participants were informed that the interview would explore eating patterns in CD. Demographic information (gender, age, years since diagnosis, body mass index (BMI)) and health information (EAT-26 and BES scores) were taken from the existing database; these measures were all based on self-report.

A semi-structured interview schedule allowed us to frame questions to fit the theoretical model of disordered eating ([6]). The interview explored key themes concerning the diagnosis of CD, the daily management of the GFD and how CD has affected participants' relationship with food and body image.

Procedure: Participants provided written consent before their interviews. The first author conducted and audiotaped the interviews. Each interview lasted between 30 and 45 minutes and was conducted in the participant's home. If any current or past disordered eating was reported, participants were asked to discuss this in more detail, and reflect on

any links with their CD diagnosis. The interviewer encouraged participants to elaborate on relevant themes.

Data Analysis: Ritchie and Spencer's ([14]) Framework methodology was used as it allows the use of a theoretically-driven framework to structure and explore the data. Framework analysis was beneficial for this study because it can include *a priori* themes drawn directly from the model of disordered eating ([6]), as well as emergent concepts.

Interviews were transcribed verbatim by the first author, and read repeatedly in order to identify key themes. These themes were developed into a framework for coding the entire dataset. Additional categories were created for data that did not fit into the framework. To enhance reliability, the coding process and emerging themes were discussed among the authors until consensus was achieved. Trustworthiness of the data was enhanced using a decision trail to ensure transparency ([15]).

Ethical Approval: Ethical approval was granted by the Research Ethics Committee, University of Birmingham.

Results

Five males and 16 females took part in the interviews, (mean age = 39 years; mean time since diagnosis = 5 years). Of these, 10 participants scored above EAT-26 and BES cut-offs resulting in them being classified as "disordered eaters". Participant information can be found in Table 1. Illustrative quotes presented are annotated with pseudonyms and participants' disordered eating status (DE or non-DE). 'Disordered eaters' and 'typical eaters' displayed significantly different BES ($t(19)=-7.09, p=<.001$) and EAT-26 ($t(19)=-.61, p<.001$) scores. There were no significant differences between participants for age, BMI or years since diagnosis. There were also no significant differences across gender for EAT-26 and BES scores.

The theoretical model of disordered eating in gastrointestinal disease ([6]), describes three stages in the development of disordered eating: adaptation to diagnosis, illness beliefs and dietary management. These stages provided the analytic framework for the hierarchical themes. Each hierarchical theme was coded in depth to identify subordinate themes. Each of these subordinate themes were explored, resulting in 17 sub-themes (see Table 2). All

themes were reported across participants but experiences and opinions differed across individuals.

1) Thoughts, Feelings and Behaviours Underlying Disordered Eating

(i) Adaptation to Diagnosis

The New Self

The diagnostic process was related to physical changes in body image, which were important in the adoption of disordered eating patterns. Disordered eaters described distress around weight changes after diagnosis. This was linked with a desire to lose weight by restricting food intake.

I liked being thin. I was over 30 and I wasn't putting on weight. I've definitely got a big belly now, I've put on weight and it's really bothering me. I really have lost a lot of confidence in terms of the way I look. So I go on more diets now, to try and get back to how I was. I'd like to be back to my pre-diagnosis weight. **(Georgia, DE)**

These weight changes were challenging for disordered eaters and Dan felt that more support could have been provided from healthcare professionals.

Associating thinness with unhealthiness is strange. Putting on weight but being healthy, it goes against the things you read about. I think the dietician could have explained that once your stomach goes back to normal there will be a process where you start to gain weight. I don't remember her explaining that. That may have helped me feel better. **(Dan, DE)**

Some individuals did not experience post-diagnosis weight changes and others felt happier with their weight once they were following the GFD. Typical eaters felt better after diagnosis because of their increased energy, which was associated with an improved body image.

The thing I've really noticed is that when I'm feeling ok, I've got so much more strength and energy. And that makes me perceive my body better. **(Amy, non-DE)**

Mourning Gluten

Participants described the challenging process of mourning gluten-containing foods after diagnosis, which was accompanied by distress. Twelve participants described a ritualistic consumption of gluten "for the last time". These feelings of loss were still present in disordered eaters and were associated with a desire to consume gluten-containing foods.

There's a certain food that I'd normally eat, I remember I cried when I ate that for the last time. I ate loads of it, to try and say goodbye. That was really upsetting. I still miss the food, it's really hard. I just want to eat it again. I get upset seeing friends eat it. **(Paula, DE)**

For typical eaters, this mourning process was brief and no longer occupied their thoughts.

There is a sort of grieving process for maybe a few months. But now it's just a part of life. There's no reason to miss food that made me ill. **(Colette, non-DE)**

After the adjustment process and acceptance of their diagnosis, participants began to develop beliefs about their CD and the GFD.

(ii) Illness Beliefs

The Dangers of Cross Contamination

Cross-contamination was frequently referred to during the interviews. However, disordered eaters were less concerned about cross-contamination than were typical eaters, and believed that accidental gluten ingestion would not impact their long-term health.

I'm rarely ill from cross-contamination, so I take risks and deal with the consequences. A tiny amount of gluten every so often won't have adverse effects on your long-term health; it just might make you feel sick. **(Julie, DE)**

Typical eaters had greater concerns around cross-contamination and went to greater lengths to avoid cross-contamination than did the disordered eaters. Louise coped with these concerns by limiting her food intake when outside of her home environment.

Sitting in the staff room with everyone else eating food, that's scary. Um, I know they're not going to touch me or make me eat it or anything but I won't eat anything. There's just too

much risk. I only eat my own foods in my own home… if I'm out shopping all day, I won't eat but I'll eat my own safe food when I get home. **(Louise, non-DE)**

For three individuals, these cross-contamination concerns extended into their own home: the kitchen was viewed as an unsafe environment and resulted in a restricted food intake.

The kitchen isn't safe. It's gluten-free, but it's more that food in general isn't safe. I get worried around food. I have a few safe things that I do eat but food has become the enemy now. It's just safer not to eat. **(Mel, non-DE)**

Response to Weight Changes due to GFD

Participants were asked about the causes of any weight changes experienced after commencing the GFD. Seventeen participants experienced weight gain after starting the GFD whereas the remainder experienced no change or weight loss. Disordered eaters attributed weight changes to the GFD and the poor nutritional quality of gluten-free foods; they responded by restricting their food intake.

And the gluten-free foods, if it's not super fatty, it's super sugary. Eating gluten-free food made me really fat. It's hard to stay slim on a gluten-free diet. I've had to go on diets to lose the weight but it's hard. **(Paula, DE)**

For typical eaters, weight changes were attributed to the recovery of the intestine and improved health.

My weight has been quite stable, I put on a bit at first but I was really underweight. I read all the books and they said that when your body recovers your weight should be normal. And that's what happened. **(Mel, non-DE)**

(iii) Dietary Management

Risk Taking

The majority of participants managed their GFD well. However, five disordered eaters reported consuming small amounts of gluten.

There was this really good sauce and I did take a really small piece of crusty bread. Because crusty bread is the thing I miss the most. And I very gingerly sort of scooped up all the sauces

and ate it. It would be a small piece that hopefully I'm going to sort of eat without my stomach noticing. **(Dan, DE)**

Not all individuals with disordered eating reported deliberate gluten ingestion and this was not recognised as a technique to promote weight loss.

For typical eaters, their concerns around cross-contamination and the fear of re-experiencing unpleasant symptoms meant that risk taking was not tolerated.

I don't take risks. I can't take risks. Gluten poisons me, why would you risk being poisoned? **(Sue, non-DE)**

2) Patterns of Disordered Eating

(i) Eating Knowledge and Practices

All participants felt that their eating patterns and the way they thought about food had changed since their diagnosis. Their thoughts and feelings about their CD affected both their attitudes towards food and the way they consumed food. Three sub-themes emerged related to these changes in eating patterns and beliefs: *food preoccupation, eating for pleasure and new eating patterns.*

Food Preoccupation

All participants reported that their diagnosis of CD had made them more aware of the foods they were consuming and more aware of the nutritional content of food. This awareness arose from the need to manage the GFD and the preparation and planning that this involved. Participants were always thinking about food, what meal they were having next and where this food was coming from. For disordered eaters, this food preoccupation dominated their thoughts.

You've got to think about the range of colours you're eating, the nutrients and about the quantity, you're thinking about a whole range of stuff. I'm a bit obsessive about food. It does change your relationship with food. You're always thinking about food. **(Paula, DE)**

This awareness of food often led to an increased awareness of the calorific content of food. Seven individuals became dissatisfied with the amount of calories they were consuming and became dissatisfied with their body image.

Since becoming coeliac I'm also a lot more calorie conscious as well. And the gluten free foods. They're full of calories and fat, and that has made me, well, fat. Now I'm much more conscious, about everything I eat. **(Georgia, DE)**

Typical eaters described an awareness of food, but they were able to integrate these thoughts around food into their life.

I'm a lot more aware of food now, it's on my mind a lot but that doesn't bother me. I might see a Chinese recipe but I'd just wonder how I could make it gluten-free. It's just a part of life. **(Richard, non-DE)**

Eating for Pleasure

After CD diagnosis, emotional relationships with food had changed. Meal times were described as challenging and eating was no longer enjoyable. For disordered eaters, a loss of pleasure around eating was common and was strongly interlinked with emotions: food became a source of distress.

Initially I was anxious. Finding out all these foods you couldn't have and thinking why the hell does that have gluten in it, was upsetting. Food is now my enemy, food kills me, food attacks me. I know that sounds really melodramatic but that's how it feels. **(Dan, DE)**

A lack of enjoyment in the eating process resulted in typical eaters simply viewing food as fuel for the body.

I've gone off food really. Food is the baddie in my life at the moment. I just eat what I have to; I've lost the enjoyment of sitting down and going out for a meal. **(Amy, non-DE)**

In comparison, the majority of typical eaters enjoyed eating outside the home, whilst managing their GFD.

It's harder to eat out but you can't let that dictate your life. I still enjoy going out with friends for a meal, I just have to be careful. **(Richard, non-DE)**

New Eating Patterns

Some participants reported an improvement in their diet since diagnosis; however, others reported eating patterns that appeared disordered in nature.

For eight disordered eaters, overconsumption of food was reported and this was linked with emotional distress. The restrictive nature of the GFD made participants long for certain foods. When these foods were available, they would be bought in bulk and consumed in a short space of time, indicating a binge-type eating pattern. However, the consumption of this food was not associated with guilt.

When you're unable to eat certain foods, you then overcompensate with other things like wine, chocolate, biscuits. It's depressing not getting these foods, so when you do, you just enjoy it. And eat loads of it. I don't feel guilty, when I eat it, I feel happy again. The cakes aren't going to be there tomorrow, so eat it while you can. **(Paula, DE)**

Some disordered eaters felt that because of the restrictive nature of their GFD they deserved to indulge in certain foods. Some participants hoarded gluten-free foods and ate them at a fast rate.

When the gluten-free Kit Kat bars first came out, I hoarded those because they were delicious. If it's good, I'll be hoarding. Sometimes I eat them all myself. I think that's probably my way of dealing with it. And I eat faster than I used to, I just eat it quickly before someone's like – no you can't eat that. **(Julie, DE)**

Other disordered eaters felt a need to limit their food intake due to concerns around weight increase since their CD diagnosis.

It's like being on several diets at once. I can't eat gluten, I eat naturally gluten-free because of all the calories in gluten-free breads and pasta, and I'm on a Slimming World diet because of all the weight I put on after my diagnosis. I just want to lose the weight. **(Martha, DE)**

Typical eaters used strategies to improve food availability. This included cooking large quantities of food and storing them to consume during the week.

I kind of, I think I make up for the fact that I can't eat gluten by baking a lot of gluten free cookies and meals. I portion them and freeze them for later in the week. **(Katy, non-DE)**

Five typical eaters developed a fear of trying new foods or trying foods in new environments. This stemmed from concerns around cross-contamination and the belief that it was dangerous to eat foods outside the home. Some typical eaters reported going for long periods of time without eating outside the home. These participants no longer enjoyed

eating in general and felt more at ease when they were not around food, which resulted in restricted food intake.

If I'm out shopping all day, I prefer not to eat. It's just not safe to eat. Eating has become scary because of my coeliac. I only eat if I'm desperate. Food is too dangerous now, when I'm not eating I feel safe. **(Richard, non-DE)**

Others felt that their eating patterns were not affected by their CD diagnosis. They were still able to maintain a nutritionally balanced diet. These participants were able to consume a range of foods both inside and outside the home, despite sticking to their GFD.

As long as I know it is gluten free, I'll try anything. I'm not a fussy eater at all. I've always been that way. The only restriction to that is whether it's gluten free or not. **(Katy, non-DE)**

Discussion

This study investigated the experiences of disordered eating in CD, in order to test a theoretical model ([6]). Disordered eaters reported eating patterns suggestive of a binge/restrict cycle, which was associated with psychological distress, poor dietary-management and a preoccupation with food.

Disordered Eaters

Disordered eaters, as determined by the EAT-26 and the BES, developed eating beliefs that stemmed from concerns around weight changes associated with commencing the GFD. These weight changes caused distress and participants found it challenging to adapt to their new body image. They described a desire to reach their pre-diagnostic weight and responded by restricting their dietary intake. Weight increase is a known trigger for disordered eating behaviours that may be viewed positively by those who are underweight at diagnosis but may be unwelcome in those who begin at a normal or higher weight ([16]). These findings are in line with Leffler et al. ([4]) who described three cases where concerns around weight increased after starting the GFD which led to disordered eating behaviours.

Distress and mourning the loss of gluten-containing foods were associated with disordered eating status. All participants experienced a mourning period, but for disordered eaters, there was an extended period of distress surrounding the loss of gluten-containing foods, that lasted for years after diagnosis. Participants coped with these feelings by

overcompensating with high energy-dense, gluten-free foods such as cakes and biscuits. Consumption of high-energy dense foods has frequently been reported in those with CD ([17]), but our results indicate that this may occur to help manage distress. Participants reported no guilt around the consumption of these foods because they felt they "deserved" to eat them. This resulted in the hoarding of foods and fast food consumption. This could be an indication of binge-eating type behaviour in a sub-group of participants, all of whom were classified as disordered eaters according to the BES ([18]).

Disordered eaters reported that overconsumption occurred in combination with restrictive eating: weight loss was promoted by restricting food intake but this resulted in a preoccupation with food and psychological distress, which resulted in binge eating. These findings are in line with Herman and Polivy's ([19]) Boundary Model, which suggests that those who restrict their intake are more responsive to external stimuli and at risk for both under and overconsumption of food. Similar patterns of eating have been described in people with Type Two Diabetics who also follow a prescribed dietary regimen ([20]). These findings highlight the complex interplay of emotions and food, which may alter eating patterns and beliefs in CD. An increased intake of high-density gluten free foods may be used to cope with feelings of distress that arise from the restrictive nature of the GFD. Mazzeo and Bulik ([21]) suggested that disordered eating arises after a stressful event as a way to manage emotions and acts as a coping mechanism.

Intentional gluten consumption to promote weight loss was not reported. When asked about gluten-consumption in an anonymised web-meditated survey, poor dietary management was associated with disordered eating ([8]). In addition, case studies have documented the interaction between intentional gluten consumption and a desire to promote weight loss through villous atrophy ([4,7]). However, only four participants, categorised as 'disordered eaters', described occasional gluten ingestion or risk-taking behaviours. However, participants may not have been willing to talk about intentional gluten consumption as a way of losing weight with the interviewer due to perceived lack of anonymity.

Low Risk Disordered Eaters

Typical eaters differed from disordered eaters in thoughts, feelings and behaviours. Despite experiencing weight changes after diagnosis, typical eaters felt healthy and energetic with increased confidence. This is in line with findings suggesting that quality of life increases after initiation of the GFD ([22,23]). Typical eaters also experienced a mourning period after diagnosis but these feelings of loss were no longer present at the time of interview. Typical eaters associated gluten-containing foods with the symptoms they had experienced prior to commencing the GFD and had no desire to consume these items again.

Caution around cross-contamination is essential for those with CD but may contribute to limited food consumption, both inside and outside the home. Some typical eaters reported going for long periods of time without consuming food because they believed that limiting food consumption was keeping them safe, particularly when outside the home. Neither the EAT-26 nor the BES captured the consequences of these cross-contamination beliefs on eating patterns. However, this form of dietary self-management may result in eating behaviours that could be considered 'disordered' (i.e. restricting and bingeing behaviours) as they deviate from the norm ([24]).

Importantly, not all participants displayed high levels of concern around food. Twelve individuals were happy to try new foods that they believed were gluten-free. These individuals described a healthy eating style and adaptive beliefs about food, with the caveat that their diet was gluten-free.

The Theoretical Model of Disordered Eating

These findings provide support for the two-pathway theoretical model of disordered eating in CD ([6]). The first pathway of the model suggests that an unwanted increase in weight after diagnosis results in the belief that the GFD is responsible for this weight gain, which results in poor dietary self-management to lose weight. Although our data suggests that distress around weight change is associated with disordered eating attitudes and behaviours, there was no evidence for the role of intentional gluten ingestion to promote weight loss. In addition, the mourning and distress around the loss of gluten-containing foods was associated with a desire to consume gluten. These findings are closely in line with the CD grief process described by Rose and Howard, whereby the benefits of following a GFD were

not always viewed as beneficial, resulting in problems with dietary management ([25]). Future revisions of the theoretical model should consider the role of distress and feelings of loss in relation to gluten-containing foods.

The second pathway describes those who adapt well to their CD diagnosis and have good dietary self-management but overly extreme concerns around cross-contamination may develop. Our findings suggest that some participants developed an extreme vigilance around food, which was associated with limited food intake and concerns around food preparation and consumption. However, these individuals did not score above clinical cut-offs on measures of disordered eating. Vigilance around cross-contamination is essential for GFD management but it is unclear from the current data whether these extreme concerns around cross-contamination are maladaptive. Future revisions of the theoretical model need to consider the types of concerns around food in those with CD to identify factors that may promote maladaptive concerns.

Strengths and Limitations

All participants were diagnosed at 16 years of age or older; however, age of diagnosis may have an impact on interactions with food, and this is often associated with the development of disordered eating in chronic health conditions ([26]). Childhood diagnosis may differ from adolescent and adult diagnosis in the risk for disordered eating patterns, as diagnosis under four years has been associated with better dietary-management and better psychological well-being whereas those diagnosed in adolescence show more problems with social interactions and more physical health problems ([27,28]). Furthermore, disordered eating attitudes and behaviours tend to be more common in healthy females ([29]). Although our sample contained both males and females, the samples were too small to explore the influence of gender on disordered eating attitudes and behaviours. Future research should explore the relationship between gender and disordered eating in CD.

The assessment of disordered eating and BMI were all based on self-report. This may be unreliable when assessing individuals who are motivated to keep their eating patterns and weight secret, as is the case in disordered eating ([30]). Furthermore, we recognise that the EAT-26 and the BES allow screening of disordered eating but cannot be used as diagnostic tools. Future research could focus on looking at those who display clinically significant

disordered eating patterns, assessed through clinical interview and the use of diagnostic tools. Furthermore, EAT-26 and BES scores were assessed between 18-63 days prior to the interview. Given the unstable nature of disordered eating attitudes and behaviours and their tendency to change over time ([31]), it would be beneficial to verify disordered eating status immediately before the interview. Additionally, the use of the EAT-26 and BES has not been validated in individuals with CD. The scales contain items such as "I find myself preoccupied with food" and "Sometimes I do not eat what I want around others because I am aware of my problem with food". As a result, there is potential for individuals with CD to be misclassified as disordered eaters on these tools, particularly as management of CD requires a focus on food intake ([32]). However, these behaviours may represent a skill used to manage the GFD as opposed to a disordered eating attitude or behaviour. At present, there is no validated tool to assess disordered eating attitudes and behaviours in CD. There is a need to consider the development of tools that may be more appropriate individuals with CD and other dietary controlled health conditions.

Despite these limitations, this qualitative study was guided by the model of disordered eating in gastrointestinal disease and allowed us to gain in-depth understanding into the application of this model to CD ([6]). The study provides insight into the types of disordered eating attitudes and behaviours and motivations behind these behaviours in CD. The BES and EAT-26 appear to be effective in screening individuals who display binge/restrict-eating patterns. However, these tools were not able to select individuals who limited their food intake due to concerns around cross-contamination. Directions for future research should focus on tools to assess concerns around food and cross-contamination in CD.

Clinical Implications

Individuals expressed a desire for more information regarding potential weight change after commencing the GFD. This is in line with previous research, which highlights the value of dietician-led services and the desire for more dietetic support in individuals with CD ([33, 34]). Furthermore, disordered eaters discussed distress surrounding weight changes at CD diagnosis. The current NICE guidelines do not recommend that individuals newly diagnosed with CD are consulted about the benefits of a nutritionally balanced GFD and how the initiation of the GFD may influence weight change and body shape, despite individuals with CD explaining the benefits of this type of support ([34]). It is recommended that research

informing clinical guidelines should focus on the role of educating all newly diagnosed individuals with CD about the nutritional content of gluten-free foods and possible weight changes after starting the GFD, as well as how to manage these weight changes.

Conclusions

This study has provided insight into the factors that may contribute to the development of disordered eating patterns in CD. The results suggest that experiences of disordered eating differ across individuals with CD but relate closely to the CD diagnosis and management of the GFD. Greater understanding is still needed, especially in regards to atypical eating patterns, which are not detected by current measures of disordered eating.

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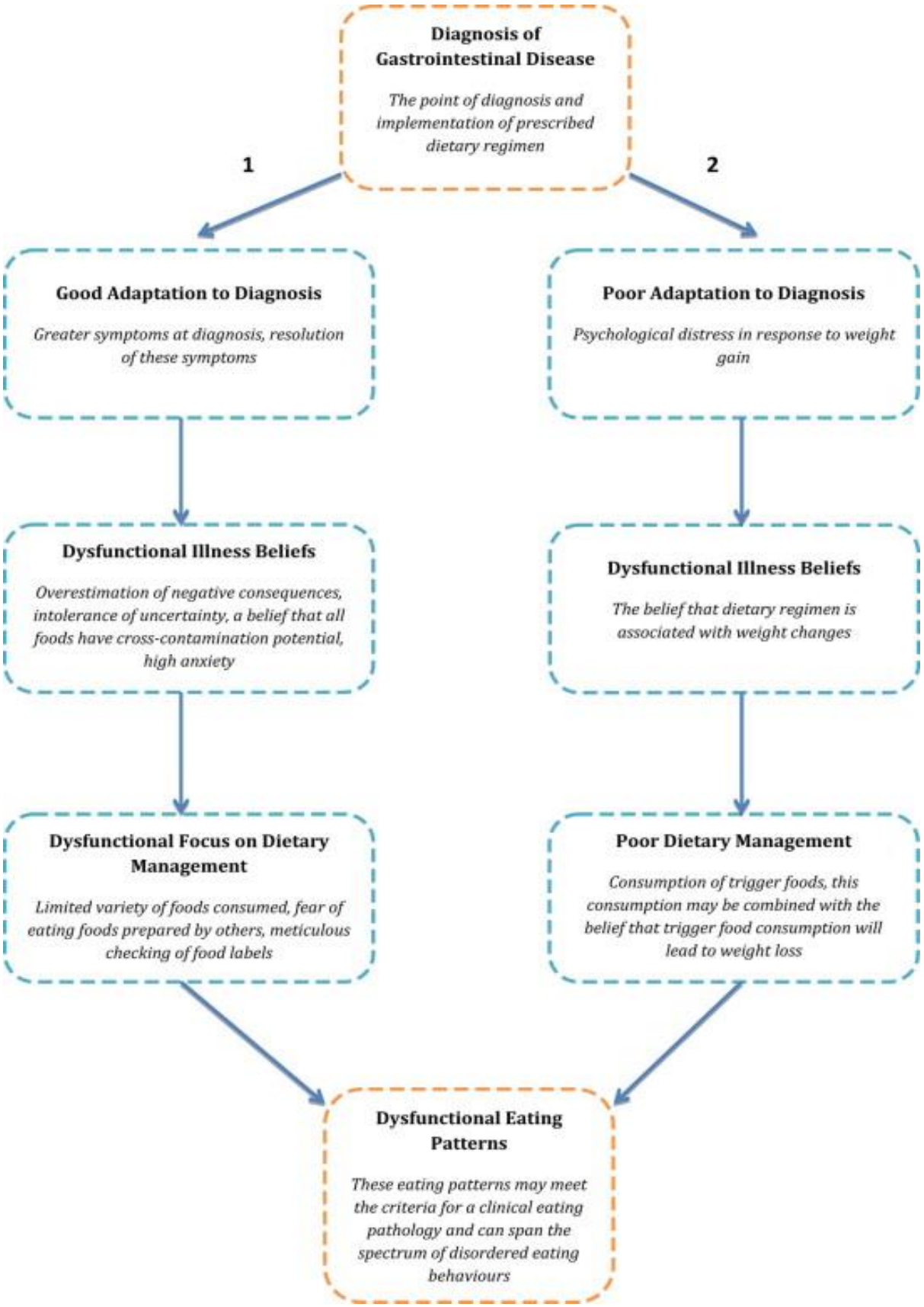

Figure One. The Satherley, Howard and Higgs' model of disordered eating in gastrointestinal disease. Figure taken with permission from: Satherley R, Howard R, Higgs S. Disordered eating in gastrointestinal disorders. *Appetite* 2015; **84**: 240-250.

555 Table 1

556 *Participant Characteristics and Disordered Eating Scores*

	Pseudonym	Age (years)	Years since Diagnosis	EAT-26 Score	BES Score
'Typical Eaters'	Katy	19	3	6	8
	John	53	2	3	3
	Mel	26	2	0	3
	Louise	29	10	8	1
	Sue	49	5	0	11
	Colette	59	19	5	2
	Richard	49	4	4	5
	Anna	28	3	7	1
	Katherine	32	3	9	5
	George	36	7	0	2
	Andrea	29	6	3	3
	Mean	*37.2*	*5.8*	*4.1*	*4*
'Disordered Eaters'	Caroline	48	3	12	23**
	Amy	48	3	26*	18**
	Paula	41	3	26*	8
	Georgia	48	2	26*	30**
	Dan	40	6	21*	25**
	Julie	22	4	30*	13
	Martha	35	4	27*	14
	Steve	38	6	19	22**
	Holly	29	2	26*	21**
	Lisa	54	8	27*	19**
	Mean	*40.3*	*4.1*	*24*	*19.3*

557 *Note*. * >20 on EAT-26; ** >17 on BES

558

559 Table 2.

560 *Final Thematic Structure and Example Quotes from Disordered and Typical Eaters*

Superordinate Theme	Sub-Theme	Example Quotes from Disordered Eaters	Example Quotes from Typical Eaters
Adaptation	*The New Self*	Caroline: I've lost a lot of confidence in the way I look. Julie: My stomach is a lot bigger now, it's hard to accept that that's healthier. Dan: My weight kept going up and down, I found that very difficult.	Sue: I have more strength and energy, so I perceive myself as better. John: My weight hasn't changed much at all. Richard: I've lost some weight, I think that's one of the benefits of being a Coeliac.
	Mourning of Gluten	Julie: Viennese whirls. I miss them, they were my favourite and I get sad thinking about them. Dan: I ate a lot of gluten, to say goodbye to the foods I wouldn't be able to eat anymore. Caroline: My diet is so restrictive, it's impossible not to miss old foods.	Richard: I don't really miss any foods because they made me so ill. Louise: It felt like a mourning for what you couldn't have, I was angry but made peace with it in the end. Sue: I feel so much better now, I don't think I could miss gluten.
Illness Beliefs	*The Dangers of Cross Contamination*	Amy: I clean the surfaces before cooking and reduce the contamination risk. Georgia: I don't let cross-contamination control me, I just do a quick check before eating. Julie: It doesn't overly concern me, I might get ill but a small bit of gluten won't kill me.	Sue: I'm worried about the crumbs, if my husband's bread is in my kitchen, I won't eat. Louise: Sometimes it's safer not to eat because cross-contamination is everywhere. Mel: I have a gluten radar on at all times, if that radar is activated, it's best not to eat.
	My GFD Makes me Fat	Georgia: Gluten-free foods are full of calories, they make me feel fat. Caroline: Gluten-free food is full of rubbish, it definitely contributed to my weight gain.	Katy: Gluten-free cakes are unhealthy but I limit them like anyone else would limit cakes. Richard: I knew that I would gain weight as my body healed.

Dietary Management	*Risk-Taking*	Paula: Sometimes I'll take a very small risk. Georgia: I think I should probably be more careful than I am. Caroline: It's hard outside the home, I may take some risks then.	Mel: Gluten is poison, I would never cheat. Richard: I'm very ill when I make mistakes, I can't let it happen. Louise: I haven't had gluten. I just don't allow it.
Eating Knowledge and Practices	*Eating for Pleasure*	Georgia: Food is my enemy at the moment. Paula: Food makes me upset. It makes me scared. It makes me jealous. Amy: Eating isn't enjoyable anymore, it causes a lot of stress, particularly outside the home	John: Food is just a tool for my body now. Sue: I've gone off food, it causes me a lot of anxiety. Richard: Eating is a lot more difficult than it used to be, it can be done but it involves a lot more planning and isn't as relaxed.
	Food Preoccupation	Caroline: I'm a lot more aware of the calories in food now and more careful about what I eat. Julie: The gluten-free foods are full of fat and calories, I just avoid them. Georgia: Food is always on my mind, I think I'm a little bit obsessive about food.	Katy: You're always thinking about food. You're always cooking food. Mel: It does make you a bit conscious about how you are with foods. Richard: Food is always on my mind but it motivates me to cook and I now want to make a gluten free cake shop.
	New Eating Patterns	Julie: I overcompensate with cakes and cookies. Caroline: I eat a limited range of foods but it works for me. Dan: I always search for the new gluten-free treats. They're hard to find, so I feel like I deserve them when I can have them.	Colette: I will eat anything, as long as it's gluten-free. Richard: I cook a lot more now and I'm more interested in cooking, which makes sourcing food a lot easier. Sue: I don't eat out as much now, but in my home it's just the same as it used to be.

561 **Appendix A – STROBE Assessment**

562 STROBE Statement

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract – see study title "A Framework Analysis"
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found - see Abstract
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported – see lines 54-74
Objectives	3	State specific objectives, including any prespecified hypotheses – see lines 68-74
Methods		
Study design	4	Present key elements of study design early in the paper – see lines 72-74; 97-100
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection – see lines 86-87; 103
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants – see lines 77-82
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable – see lines 80-85; 94-96; 98-100
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group –see lines 80-85; 94-96; 98-100
Bias	9	Describe any efforts to address potential sources of bias – N/A
Study size	10	Explain how the study size was arrived at – see lines 88-90
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why – see table one; see lines MIGHT NEED TO ADDRESS THIS
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding – see lines 112-121
		(*b*) Describe any methods used to examine subgroups and interactions N/A?
		(*c*) Explain how missing data were addressed – see lines 90-93
		(*d*) If applicable, describe analytical methods taking account of sampling strategy – see lines 88-90

		(*e*) Describe any sensitivity analyses N/A
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed – see lines 88-90
		(b) Give reasons for non-participation at each stage – see lines 88-90
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders – see lines 125-128 and Table One
		(b) Indicate number of participants with missing data for each variable of interest – see line 88-90
Outcome data	15*	Report numbers of outcome events or summary measures – missing data was not analysed so numbers are the same throughout
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included N/A
		(*b*) Report category boundaries when continuous variables were categorized – lines 80-82
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period N/A
17Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses N/A
Discussion		
Key results	18	Summarise key results with reference to study objectives – see lines 312-315
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias – see lines 402-428
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence – see lines 438-442.
Generalisability	21	Discuss the generalisability (external validity) of the study results – see line 399 ???
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is

based x- see lines 443-444

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